

# HCP CRCSN Notification Follow-Up Policy and Guidelines

## For

Colorado Responds to Children with Special Needs (CRCSN)

# HCP Program CRCSN Notification Follow Up Policy and Guidelines

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### What is CRCSN?

#### What is Colorado Responds to Children with Special Needs?

Colorado Responds to Children with Special Needs (CRCSN) is the birth defects monitoring and prevention program at the Colorado Department of Public Health and Environment. The program began in 1989 under the guidance of an advisory board of parents, physicians, advocates, and representatives from state agencies.

#### What is the purpose of Colorado Responds to Children with Special Needs?

- to maintain a statewide, database of pregnancies and young children with birth defects, developmental disabilities, or risk factors for developmental delay
- to monitor and investigate the occurrence of birth defects and developmental disabilities
- to prevent birth defects and secondary disabilities due to birth defects and to help connect children and families with early intervention services in their communities
- to provide accurate, aggregate statistics and an unduplicated count of children with special needs to other programs and agencies for program planning
- to provide statistics to researchers studying causes and risks, the ultimate goal being to prevent future birth defects and developmental disabilities

#### What information is collected?

Colorado Responds to Children with Special Needs collects information about birth defects among Colorado residents diagnosed before birth and up to age three with one of the conditions eligible for the program. Eligible conditions are listed on a following page. Children meeting these criteria are identified from many sources including hospitals, vital records (birth, death, and fetal death certificates), the Newborn Genetic Screening Program, the Newborn Hearing Screening Program, laboratories, prenatal diagnostic centers, physicians, and genetics, developmental, and other specialty clinics.

About four percent of all births have major congenital anomalies. About 8,000 children or 13 percent of all the births in Colorado each year are identified because they meet CRCSN eligibility criteria, which include risks for developmental delay.

#### What is CRCSN's authority?

The legal authority to collect birth defects information is based on a statute authorizing the Colorado Department of Public Health and Environment to develop and maintain a system for detecting and monitoring conditions that contribute to preventable or premature sickness, disability, or death (C. R. S. 25-1.5-101 to 25-1.5-105). Under Colorado Board of Health regulations (6 CCR-1009-7) hospitals, health care facilities, and laboratories are required to report birth defects, developmental disabilities, and chromosomal abnormalities diagnosed prenatally and up to age three. Physicians are required to report suspected or confirmed fetal alcohol syndrome under age ten, autism under age ten, and muscular dystrophy.

#### Does CRCSN focus on any special conditions?

The program has several surveillance and prevention projects that focus on specific conditions including fetal alcohol syndrome, autism, neural tube defects such as spina bifida, cleft lip/cleft palate and muscular dystrophy. CRCSN collaborates with other agencies, programs, and family support groups concerned with these conditions. Additional information on these projects can be obtained by calling CRCSN.

Program staffs also respond when citizens are concerned about birth defects in their communities.



## Eligibility Criteria for CRCSN

- ✓ Resident of Colorado
- ✓ Diagnosed prenatally to the third birthday
- ✓ Diagnosed as having one of the following conditions

#### **CONGENITAL ANOMALIES**

Central nervous system

Cardiovascular Circulatory Respiratory

Eye, ear, and face

Orofacial

Gastrointestinal Genitourinary Musculoskeletal

Chromosomal abnormalities
Congenital anomaly syndromes

## GENETIC, ENDOCRINE, & METABOLIC DISORDERS

Phenylketonuria (PKU) Congenital hypothyroidism

Hemoglobinopathies

Galactosemia

Cystic fibrosis

Biotidinase deficiency

Congenital adrenal hyperplasia Disorders of amino acid transport

and metabolism

Disorders of carbohydrate transport and metabolism

Lipidoses

Disorders of copper metabolism

Other disorders of purine and

pyrimidine metabolism

Mucopolysaccharidoses

## MEDICAL DIAGNOSES & RISK FACTORS FOR DEVELOPMENTAL DELAY

Birth Outcomes and Perinatal Conditions Birth weight less than 1500 grams Prematurity less than 32 weeks gestation

Small for gestational age

APGAR 3 or less at five minutes Meconium aspiration syndrome

Birth trauma

Intracranial hemorrhage Convulsions / seizures

Drug withdrawal syndrome in the

Newborn

Noxious influences affecting fetus

Fetal alcohol syndrome

Congenital perinatal infections

## Sensory, Development and Growth Conditions

**Hearing Loss** 

Blindness and low vision Retinal degeneration

Speech and motor delays

Growth and weight delay

Mental retardation Infantile cerebral palsy

Dystrophy: muscular and spinal

Degenerative CNS / Cerebral Lipidoses

#### Other Risk Factors for Developmental Delay

Encephalitis

Meningitis

Injury: head and spinal cord

Cerebral cysts

Child maltreatment syndrome

Chorioretinitis

Infantile spasms

Renal tubular acidosis



## How CRCSN Helps Families

#### **How Do Communities Use CRCSN?**

CRCSN collaborates with the Health Care Program (HCP) for Children with Special Needs and local public health agencies and community nursing services to connect families with services in their own communities. A representative such as a public health nurse calls, visits, or writes the family. Many families with young children are not aware of the resources available to them and must search out services on a hit or miss basis. The services may include:

- Developmental evaluation
- Early intervention programs
- Physical and speech therapy
- Public health nursing
- Specialty medical care
- Nutrition services
- Parenting classes
- Parent support groups
- Financial assistance

#### How are Children Identified by CRCSN?

The majority of the children referred to the local agencies are identified through hospital discharge data. Experience shows that the local agencies are already aware of and have had contact with about a fourth of the families.

#### **Selecting Children for Notification**

Prior to notifying the local agencies, children's names are matched to death certificates to ensure that the families of children who have died are not contacted. Single minor conditions that are not risks for developmental delays or special needs are excluded from notification.

## Using the CRCSN Web Site

#### How to Find the CRCSN Web Site

The computer address for this web site is <a href="https://www.cdphe.state.co.us/dc/crcsn/crcsnhome.asp">www.cdphe.state.co.us/dc/crcsn/crcsnhome.asp</a>
You can type this address into the address line on your web browser. This will bring you to the CRCSN home page, which gives a brief overview of the purposes of CRCSN. When you are ready to obtain data from the web site, click on the option "Introduction to Tables." The text describes the layout of the tables and the type of data that you will find in them. Reading this page at least once is recommended. The next time you come to this point, you can click on the words "Data Tables" near the top of the introduction and it will take you to the list of tables.

#### What Data can be found there?

"In each of the tables, major congenital anomalies appear at the beginning, followed by congenital anomalies and related conditions ordered by body system." Data are presented in two different table formats and are either for all Colorado residents or by county of residence at the time of birth. Since some children have more than one of these conditions and since the categories listed in these tables are both general and specific, children may be listed in more than one category on these tables. Be aware that summing the rows in different directions will not add up the same way that they would if all children were only listed once on the table.

You can obtain counts by year of birth for children who were diagnosed with many different types of congenital anomalies, either by broad categories such as "major congenital anomalies" or by more specific categories. (For a list of the possible categories, click on the last table on this list, "ICD9-CM Codes for Diagnostic Categories,

#### How can I find data for my county?

There are two different methods of finding data specific to your county. The first way is to click on the first option listed, "Query and Summarize Data from the CRCSN Dataset." This brings you to the Colorado Health Information Dataset, or "COHID." You will notice from the other options listed at the left side of the screen that you can also use this page to access other types of information about state data, including birth and death statistics, cancer statistics ad behavioral risk factor data.

#### **Summary of Steps to Find County Data**

From your Web Browser, go to <a href="https://www.cdphe.state.co.us/dc/crcsn/crcsnhome.asp">www.cdphe.state.co.us/dc/crcsn/crcsnhome.asp</a>
Select Introduction to Tables
Choose Query and Summarize Data from the CRCSN Dataset
Select your County (or the county of interest)
Select the time period that you want to look at (1999-2003 for this example)
Select race and ethnicity of mother (all races, all ethnicities for this example)
Select age range for the children (all ages, for this example)
Select the gender of the children (all genders,

Select the type of congenital anomaly or birth defect that you want to investigate (major congenital anomalies, for this example) Select count or rate (rate, for this example) Click on **submit.** 

for this example)



## Tips on Responding to Confidentiality Questions

From CRCSN: Margaret Ruttenber, 303-692-2636, Program Manager

NOTE: Parents often ask about financial assistance. CRCSN does not provide any direct care. Provide the family with the number in Health Care Program for Children with Special Needs (HCP) in CDPHE x2370 (HCP is located on the 4<sup>th</sup> floor in Prevention Services Division)

#### Negative Authorization SAMPLE SCRIPTS

TIPS: Have the log, or sheet of paper handy. You will want to jot down what the parent says.

NOTE: Since federal laws govern the vital record, CRCSN does not know the identity (or contact information) of the child or the parent when information is reported from the birth certificate. Some parents will identity themselves to you.

The Authorization process permits CRCSN to learn the name of the child (as well as other contact information) so that the child may be referred to local agency services.

However, if the parents 'refuses' to authorize a release of contact information to CRCSN, the birth defects program will still have the statistical information (i.e. the child is still in the birth defects program. ALL other data sources report cases with name and contact information, so in time, many of the Vital Record cases are merged with new in-coming case reports.

#### Parent phone calls: After the introductions.

CRCSN: 'How may I assist you'?

The parent usually says: I received a letter from the health department. What is it about? How did you get my name? Is this the same as 'x' letter I also received from the government?

CRCSN: Verify that the letter is YELLOW. If not yellow, try to figure out what the letter says so that you can direct the person to the correct program in CDPHE

CRCSN: This is a program at the Colorado Department of Public Health and Environment called "Colorado Responds to Children with Special Needs". It is the birth defects monitoring program, and we also identify a child with a developmental delay or at risk for developing a secondary delay.

NOTE: The latter part of the last sentence is emphasized to decrease the fear that ONLY a birth defect is reported.

NOTE: Sometimes a parent questions how the health department got the child's name etc. Answer: The birth defects program has been operating since 1989. By law, health care facilities, and other sources of medical information, are required to report suspected or confirmed eligible conditions to the health department (the birth defects monitoring program (Colorado Responds to Children with Special Needs).

CRCSN: Since you received a yellow letter it means that something was reported from the Birth Certificate that allowed your child to be in the birth defects program.

We do not know what was specifically reported from the BC, only that one of the criteria was met.

Conditions reported from the birth certificate are:

- 1. Low birth weight  $\leq$  1500 grams (this is  $\sim$ 3.3 lbs)
- 2. Prematurity < 32 weeks (40 is usual term delivery)
- 3. Apgar Score at 5 minutes:  $\leq$  3 (range is 10 0 (low)

CRCSN: Do any of these conditions refer to what you were told about your child? Do you remember if your child was low birth weight, or premature, or had a low apgar score. (If a PROBLEM, see below)



NOTE: APGAR is a 'viability response' score of an infant at 1 min, 5 min, and sometimes 10 min right after birth. Respiration rate, cardiac, and other key 'life' factors are rated. The scores are in the range of 10 – 0 (low), so you can see that the CRCSN criteria <. 3 means the child was in significant distress. For example: An Apgar score of 1, 0 means that the child died less than or equal to 5 minutes of life; 0,0 is equal to a stillbirth. Do a search on the web site for more information on APGAR.

CRCSN: The letter you received is part of an authorization process. If you would like to learn more about child development or about other services available to you in your local community, HOLD ONTOTHE LETTER. You will be contacted in about a month from one of our partners in your local health department

If you DO NOT WANT A CONTACT (Do not want to release your child's name to the birth defects program), check the box on the letter and mail in the postage paid return envelope.

NOTE: You can give the parent the name of the local agency. You will need to ask for county where the parent lives. April Montgomery has the current listing.

#### CRCSN Finishing the phone call:

Thank the parent for taking the time to call, for considering releasing the child's name. **Offer to continue to help if they have questions.** 

Additional scripts:

Problem with case report that comes from the vital record:

CRCSN: "Since you do not recognize any of the criteria that could have been reported from the Vital Record, I would like to investigate further. We want to make sure the information that is reported is correct. Would you be willing to give me your child's name, date of birth, and hospital of birth. I will contact the person in the health department's vital records section, and they will contact the hospital." I will call you back when I receive the information. What is your child's name, DOB? What number may I call you back? Would you be willing to give me your name?

NOTE: Some parents do not want to give a phone number. In these cases, tell them to call you back in 7 days (this is a good time period, although most investigations only take 2-3 days).

PROBLEM with Parent understanding how information may be collected from a medical record.

Suggest that parent request copy of medical record

CRCSN: "You, as a parent have the right to get a copy of the medical record of your child. This way, you will be able to see how information is put together in a medical record and why a diagnosis was reported to the birth defects monitoring program."

Confidentiality issues specific to calls

- a. Log the calls in the secured logbook as the call occurs. Use the form. Include dates and times of all communication attempts, incoming and outgoing calls. Record whether the call came over the disease line, and note when the disease line call was forwarded to you.
- b. Parent calls: Guide the parent/caller into TELLING YOU why he is calling, questions he has, and answers he wants.
- c. CRCSN staff calls a parent back and leaves messages:

**Verify**, to the best of your ability that the person you speak with is the person you should be talking to! some families have 'extended family members' or friends to answer the phone. **Refrain** from supplying a lot of information on a phone message system, or with another person. (This could potentially be a breach of confidentiality). Leave your name and phone number only.



d. Disclosing information. As stated above, with case reports from the vital record, CRCSN is unaware of name, diagnosis, or other contact information. However, CRCSN staff must still be cautious in disclosing information that can be mis-used

CAUTION: A letter can be sent to an address that is no longer valid for the family;

A letter can be sent to a Foster parent address;

A letter can also be re-directed via mail service to another residence.

CAUTION: Teen moms may receive the letter. The teenage mother, who is also a MINOR, is the one responsible for the child (also a MINOR). Be cautious of a relative who wants to gain information.

NOTE: CRCSN staff must use discretion with Spanish translation issues. Often other persons will 'translate' for the parent who does not understand the technical issues, or does not understand CRCSN staff. In this circumstance, it is better that the Spanish-speaking parent be as involved as possible through the interpreter on their end of the conversation.

## MORE on LOCAL Agencies –Community Referral To answer the questions, why was the letter sent, what is the Notification of Referral to Services program about...etc?

CRCSN: The Notification of Referral to Services is part of the birth defects monitoring program. It is a way to help connect children and families to services in their local communities. It is a way to provide information that may be useful now or in the future. It is a way for families to know what is available in their communities; it goes beyond the medical condition and includes other family support concerns. The Public Health Nurse or staff from the Public Health agency the family may phone call, send a letter, or visit with the family. The time lag between the authorization letter process and contact with the Local agency is about 4-5 weeks.

NOTE: Speak positively about the Notification of Referral to Services program. Use words like enhance, supplement, support, opportunity, awareness, and promotion of optimal development for children.

NOTE: CRCSN is NOT connected to Social Services. (This is a HUGE concern to parents)

Types of Services: Varies in communities but may include:

Early education
Physical and speech

Physical and speech therapies Special equipment needs Public health nursing

Nutrition services

Parenting classes

Parent support groups



### **HCP CRCSN Care Coordination Policies**

#### A CRCSN Notification Follow-Up

#### **PURPOSE**

The purpose of this policy is to ensure that children identified by CRCSN, with or at risk for special health care needs and their families, are consistently connected with appropriate health care and community resources. This occurs through the efforts of HCP Local Health Agencies.

#### **RESPONSIBILITIES:**

#### **State HCP Responsibilities:**

- HCP Director:
  - o Communicates to the HCP Contractors regarding the overall CRCSN Follow up Program
- Nursing Consultant: Care Coordination/Specialty Clinics (AKA: (Care Coordination/Specialty Clinics Program Manager)
  - Assures compliance with the CRCSN Follow up Program policies, procedures, and contract expectations
  - Develops and implementation of the CRCSN standards of care related Notification Follow Up
  - o Development, implementation, and updating of CRCSN Site Manual
  - o Development and updating of CRCSN Notification Follow up Policy and Procedures
  - Development of, implementation, and evaluation of CRCSN Training Oversight
  - Monitoring of CRCSN Follow Up
- HCP Data Owner (liaison to the state NEST/HCP CHIRP system) provides:
  - Development, implementation, and updating the CHIRP User Manual
  - Training related to CRCSN entry into CHIRP and overall CHIRP Orientation
  - Implementation of CRCSN related data reports to State and HCP contract offices

#### **Regional Office Responsibilities:**

- Identify agency staff who will complete the CRCSN Notification Follow Up and assist with auditing, including:
  - o Procedures for receiving CRCSN Notification Alerts
  - Procedures for CRCSN Notification Triage (determination of follow up and assignment of care coordinator)
  - Procedures for CRCSN Notification Determination of Care Coordination Level.
- Notify the State HCP Data Owner of names of staff involved in local CRCSN Notification Follow up.
- Provide CRCSN orientation to local agency staff and HCP Contract Offices within the region including:
  - o CRCSN Site Manual
  - o CRCSN CHIRP User's Guide
  - o CRCSN Care Coordination Policy and Guidelines.
- Provide technical assistance to the HCP Contract Offices within an HCP Multi-County Regional Office
- Monitor the HCP Contract Offices CRCSN Notification Follow up capacity and quality of implementation.

#### **HCP Contract Offices Responsibilities:**

- Designate agency staff responsible for the CRCSN Notifications and notify Regional Office Team Leader of the CRCSN staff, name, contact information, or of any changes in assigned staff.
- Check for CHIRP Notifications monthly on or about the 5<sup>th</sup> 10<sup>th</sup> of the month for any CRCSN Notifications.
- Establish agency CRCSN Notification Triage Procedures that will determine whether or not CRCSN Follow up is warranted.

- The determination is based on agency *capacity and prioritization* of notifications based on the effort required to follow up and respond to CRCSN Notifications.
- Maintain confidentiality of the family's and child's information. (See CRCSN Information Confidentiality Policy and Procedure.).
- Information may be shared between the health department programs such as WIC, Prenatal Plus, or Nurse-Family Partnership programs only.
- If CRCSN Notification Follow up is warranted, make at least two (2) attempts to contact a family, which may include:
  - o Two letters
  - A letter and a phone call or face to face visit
  - o Two phone calls
- Complete the electronic "Reply" to CRCSN Notifications via HCP CHIRP <u>within 90 days</u> of the CRCSN Notification date, entering:
  - o Decision not to contact the family due to agency capacity.
  - Efforts for attempted contacts
  - o Outcome of the contact with the family.

#### **GUIDELINES:**

- Before completing the electronic "Reply", the care coordinator should wait approximately 2 weeks
  for each attempted contact to see if a family responds to correspondence and/or other attempted
  contacts. Once the "Reply" is saved in HCP CHIRP it cannot be revised. NOTE: You do not
  need to wait to reply to the CRCSN Notification after you have made your two attempts to contact
  the family and the 2 weeks has passed. Thus, you do not need to wait the full 90 days for a
  family to respond to your attempted contacts and reply to the Notification.
- Use the highest level of contact with the family in documenting the "Type of Communications" for the follow-up "Reply." (E.g. If a family received a letter, a phone call, and a one-on-one visit, the reply needs to be "one-on-one visit").
- If a child moves to a different HCP site before a CRCSN notification is received, HCP staff transfers the child's record to the site where the child is currently living. That site should enter the "Reply" into HCP CHIRP.
- The HCP CHIRP Help Line (303-692-2383) will provide technical assistance for documenting CRCSN Notification Follow up in HCP CHIRP.
- With parents' approval and consent, the CRCSN Notification Follow up Program provides an
  opportunity for systems building through contact with primary care providers and partners such as
  Part C.

#### **PROCEDURE**

#### State HCP Office through the NEST:

 Send the electronic CRCSN Notifications monthly through the HCP CHIRP System to HCP Regional Offices.

#### **HCP Regional Offices:**

- 1. Check HCP CHIRP Notifications monthly.
- 2. Assign a care coordinator for CRCSN Notifications for your agency and for all other HCP Contract Offices in your region.
- 3. Send an email to all HCP Contract Offices in your region that have CRCSN Notifications. Inform them that the Notifications are ready to be viewed and processed through HCP CHIRP.
- 4. Print the two monthly CRCSN reports (listed below) and follow up with the HCP Contract Offices as needed.
- 5. CRCSN Notifications Current (# 15)
- 6. CRCSN Notifications Outstanding (# 14)
- 7. Provide assistance with CHIRP documentation as needed.

#### **All HCP Contract Offices:**

- 1. Establish criteria for CRCSN Notification Triage for your agency. Inform the Regional Office Team Leader if there are vacancies and the Regional Office assistance is needed to assist with replying to the Notifications.
- 2. Complete the CRCSN Notification Triage to determine need for CRCSN follow-up based on a variety of factors listed on the notification <u>and</u> your agency's capacity for CRCSN follow up.
  - Using the review process for CRCSN Notifications determine the need for notification follow up based on:
    - o Child's Age
    - o Diagnosis
    - o Length of hospitalization
    - Potential for needed HCP services
    - o Currently known or previously known to HCP
    - o Currently known to be involved with other community services
    - Circumstances that may not warrant HCP notification follow up include:
      - o Family has not responded to multiple previous attempted contacts.
      - o Child is terminally ill or known to have died.
      - Child is already receiving other public health services (WIC, Nurse Family Partnership, Prenatal +) or early intervention services.
      - Child whose diagnosis and/or hospital length of stay would indicate that the medical condition would not likely require HCP services (e.g. very brief length of stay for hearing loss-PE tubes.)
  - Use the following criteria to determine the agency's capacity for follow up:
    - Staffing levels or vacancies
    - o Other public health needs (H1N1 or other outbreaks)
- 3. If the CRCSN Notification *does not warrant* notification follow as specified in the previous section, select **No Communication**
- 4. If the HCP CRCSN Notification *does warrant* notification follow up a minimum of two (2) attempts to contact families are to be made.
- 5. Attempt to contact the family with the information provided on the HCP CRCSN Notification, either by letter or phone.
  - If there is no response from the family after the two attempted contacts make the appropriate selection in the **Reply** tab in CHIRP.
  - If the family is contacted the **HCP Intake Interview** is completed to determine the need and desire for HCP Care Coordination and the level of care coordination to be provided
    - Level 1: Completion of the HCP Intake Interview and referrals only.
    - Level 2: Care Coordination Assessment and Plan
    - o Level 3: Intensive Care Coordination
  - If the family is contacted and does not have concerns or needs, reply as "no concern'
  - Document Care Coordination Assessment and Plan in CHIRP
  - Complete the primary care provider and insurance screens in CHIRP.



#### 6. Complete the CRCSN Notification Response:

• Identify the appropriate "Type of Communication" for the highest level of contact.

Type of Communication	Definition
1 - One-on-One	Contacted: Includes any "face-to-face" communication.  Home visit or office visit is the most common. (It is assumed that this would most likely be after contacting family by phone or letter).
2 - Phone Call	Contacted: Phone call communication was completed or attempted. (one-on-one visit was not done)
3 - Correspondence	Contacted: Letter or e-mail sent to family with information about HCP.
4 – Consultation with Others	Consultation: Contacted someone other than family about the child to determine the need for f/u. Examples: PCP, TCH Liaison, Part C, or public health program/staff. This may also is used be to document a review of the child's records to determine if F/U needed.
5 - No Communication	No attempt to contact the family was made. Contact was not completed with family and no consultation with others.

#### 7. Complete the Reply Response:

Send CRCSN Reply to CRCSN at the Colorado Department of Public Health and (CDPHE) through HCP CHIRP

#### • Notification Communication Reason:

Reason	Definition
Unknown	Child is unknown to HCP CHIRP
Known – Closed	Child is known to HCP CHIRP but has been closed.
Known – Level 1	Child is known to HCP as receiving Level 1 Care Coordination at the time of the Notification from CRCSN
Known – Level 2/3	Child is known to HCP as receiving Level 2/3 Care Coordination at the time of the Notification from CRCSN

## • Reply Results in HCP CHIRP for CRCSN Notifications (Documented by HCP –Sent to CRCSN)

Reply Results	Description
HCP Level 1	Provided Level 1 to an any child (know or unknown)
HCP Level 2/3	Currently receiving or starting HCP Level 2/3 Care Coordination
Already in Non-HCP Services	Family indicates they are receiving services from other source.  Does not want or need HCP services
Family has No Concerns	Family not concerned about child's health and development. Diagnosis is not known or appropriate according to the family.
Child out of Home	Child adopted or in foster care. Unable to contact foster family
Terminally III/Deceased	Family shares the child is terminally ill or deceased Does not want or need HCP services
Moved out of state	Family is known to have left the state.
Lost to F/U	Phone disconnected, insufficient address and mail returned by USPS
No capacity	HCP office unable to provide follow-up due to capacity issues such as vacancies or other public health issues (e.g. H1N1)
Diagnosis Low Priority	Diagnosis is determined to be lower priority for follow-up due to staff priorities/capacity. <b>Use only if diagnosis is low priority</b>
No Response from Family	Left phone message or sent letter that wasn't returned undeliverable plus a 2 <sup>nd</sup> attempt that did not result in family response.

#### **B** CRCSN Information Confidentiality

#### **PURPOSE**

The purpose of this policy is to describe the appropriate sharing of CRCSN information on children/youth and their families by the HCP Contract Offices according to the Health Insurance Portability and Accountability Act (HIPAA) statutes of 1996 that defines health information as "any information, whether oral or record, in any form or medium" that connects or links any potentially identifiable individual with any physical or mental health or condition.

#### **POLICIES**

#### General:

- References:
  - Colorado Revised Statutes 25-1.5-101 to 25-1.5 105
  - Board of Health Rules and Regulations Pertaining to Detection, Monitoring, and Investigation of Environmental and Chronic Diseases (6 CCR 1009-7 25-1.5 105) authority to collect information regarding conditions such as birth defects
- Within these statutes, it states that such information held by state and local health departments "shall be strictly confidential. Such reports and records shall not be released, shared with any agency, or institution, or made public, upon subpoena, search warrant, discovery proceedings, or otherwise, except..." under certain limited circumstances.
- Releasing confidential public health reports or records is identified as a Class I Misdemeanor.
- Because CRCSN is a secondary holder of data, there are stricter confidentiality protocols and protections than may have been with the original source.
- Under the State Board of Health Regulations, state health department programs such as CRCSN and HCP and local health departments and community nursing services can share confidential information about individuals with eligible conditions with one another. Each agency and their employees are subject to the statutes.
- Every employee having access to CRCSN information should be given a written explanation of the confidentiality requirements before having access to confidential data.
- Each organization must obtain a written release from the parents before sharing personal identifying information with any other agency

#### State Office Responsibilities:

Provide contract agencies with appropriate information and training regarding CRCSN confidentiality.

#### Regional Office Responsibilities:

 Provide orientation regarding "Health Information Confidentiality" to new HCP Team members in local HCP Contract Offices involved with CRCSN.

#### **HCP Contract Offices Responsibilities:**

 Maintain appropriate confidentiality of CRCSN child/youth information when providing CRCSN Follow Up.

#### **GUIDELINES**

CRCSN collects information from multiple sources such as hospital discharge data, vital records, specialty clinics, and other programs. The majority of the infants and children who are referred to HCP are identified from hospital discharge data or birth certificate data

See Tips on Responding to Questions about Confidentiality



#### **PROCEDURE**

#### **HCP Regional Offices:**

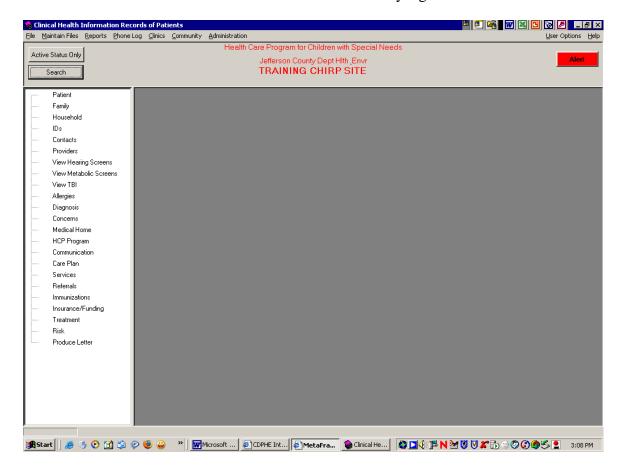
 HCP Regional Offices may share CRCSN information about a family and child/youth with other HCP Contract Offices in order to follow up on the CRCSN Notifications.

#### **HCP Contract Offices:**

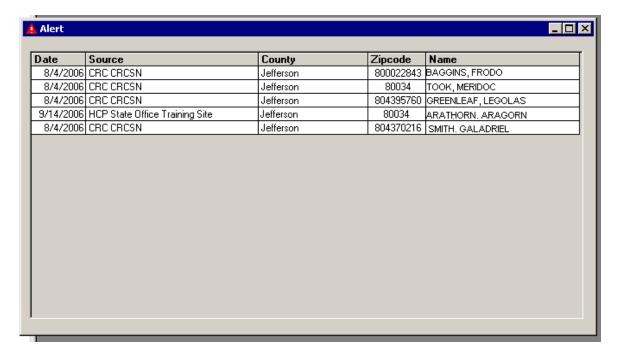
- May communicate with other public health departments or nursing services agencies such as Women's Infants and Children's (WIC) programs, Immunization Programs, Nurse Family Partnership programs, prenatal programs, or public health nursing in order to determine current or needed services for a child
- 2. When attempting to contact a family about a CRCSN notification by phone:
  - Phone message information should not include the family or child's name or the reason for the call. Only leave the caller's name and contact information.
    - Verify, to the best of your ability, that the person you speak with is the person you should be talking to! Some families have 'extended family members' or friends to answer the phone.
    - Refrain from supplying information on a phone message system, or with another person, as this may be breach of confidentiality.
- In order for the HCP Contract Offices to communicate with anyone other than public health or nursing agencies about the CRCSN information, the agencies must have written consent from the family to allow HCP to consult with them.
- 4. In order to avoid duplication of services for families, HCP Contract Offices may review a list of children enrolled in Part C when families have given consent for information to be shared with HCP or the health department
- 5. The intent of the CRCSN Notifications is to follow up with families in order to advise them of HCP services and connect them to community services. However, when a family moves or cannot be located, contact with the originating hospital, referral source, or any other agencies to obtain new addresses or contact information may not be done. This would breach confidentiality. The Notification Reply would indicate "Lost to Follow up."

#### CRCSN NOTIFICATION PROCESS in CHIRP

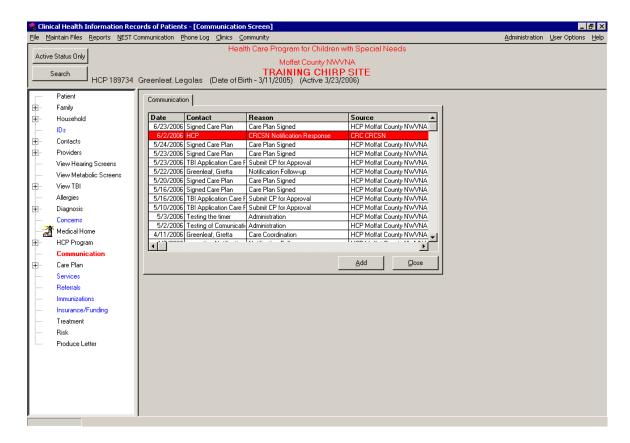
- 1) CRCSN sends a data file to the NEST with one transaction for each child determined through the CRCSN program process to possibly need public health referrals or care coordination.
- 2) The data file is processed through the NEST and the data is routed to HCP/CHIRP.
- 3) HCP/CHIRP uses the NEST identification code to match to an existing HCP patient or the resident county (if no matching NEST identification code exists on HCP/CHIRP) to determine into which HCP site to place the notification.
- 4) HCP/CHIRP generates a communication with a required REPLY.
  - a. If the child is already known to HCP/CHIRP, the communication is added to the existing child's record. The care coordinator on HCP Program and staff with "Notify" authorization will receive an ALERT for this child.
  - b. If the child is not known to HCP/CHIRP, the child and CRCSN data is added to HCP/CHIRP. Each HCP staff member in the child's site with "Notify" authorization receives an ALERT for this child the next time they sign on.



5) The RO HCP staff with the "Notify" authorization, upon receiving the red ALERT button when they sign on should click on the button to see a display of all the ALERT communications within the site they are currently signed into.



- 6) The RO HCP Staff can select a child from the list by moving the cursor to the line with the name they want to select and click on that line to see the CRCSN Notification Communication.
- 7) The next screen presented will be the communication list for the child selected. Any outstanding Notification (still active) will be highlighted in RED.
- 8) An active ALERT is a communication that has been created by CHIRP as a result of an activity occurring within the system and contains information about the child, which should be known to those active in providing care coordination for the site where this child resides.
- 9) If a second Notification is received from the same source (i.e., CRCSN) and for the same child, the second and subsequent notifications will be informational only and will require the RO HCP Staff to review the information and indicate that the information has been reviewed by clicking on the VIEW button.
- 10) The CRCSN Notification Communication is (RED) and will require either a REPLY or at least a VIEW.
- 11) The RO Staff will be presented with either a REPLY or a VIEW button by CHIRP depending on the existence of another Active Notification.
- 12) ONLY ONE REPLY NOTIFICATION CAN BE ACTIVE FROM THE SAME SOURCE FOR A GIVEN CHILD.

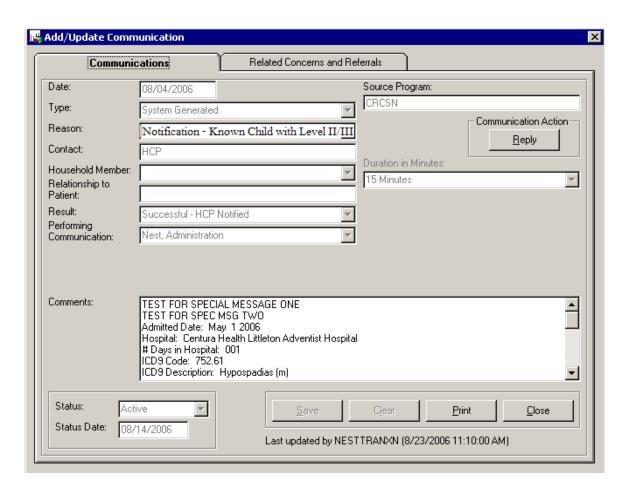


Note: The Communication node in the tree is red and the notification communication in the list is in red.

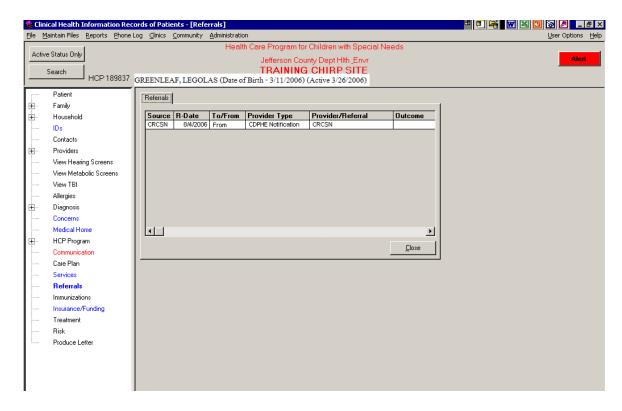
- 13) The communication in the list remains red until HCP staff performs the View or Reply:
  - a. View is needed for:
    - i. Transfers,
    - ii. Updates,
    - iii. Patient Association (assignment)
    - iv. Subsequent Notifications from the same source with a current ACTIVE notification
  - b. Reply is needed for:
    - i. Notifications from CRCSN
    - ii. Future notifications from NBH and TBI and future integrated programs.
- 14) The Communication node in the tree remains red as long as there is at least one communication that needs a View or Reply action for the displayed child.
- 15) The Alert button continues to show until all communications for this signed on user have been satisfied (either the user has Viewed or the Reply is completed) for all children having an outstanding communication on the current site.
- 16) A signed on user receives an Alert if a child has an ALERT communication and
  - a. For non-notification ALERTS: the user is listed under the Provider node for the patient and has an active association (not closed or archived).



- b. OR for notification ALERTS(either REPLY or VIEW): the user is the child's care coordinator and/or staff with "Notify" authorization.
- 17) RO personnel are responsible for CLOSING Provider associations that no longer apply. This is done by changing the status to "archive" on the provider screen in the child's record.
- 18) Read Only Screen to view the CRCSN Notification Data



- 19) The reason will indicate the status of the child with respect to HCP when the Notification was received. Examples:
  - a. Notification Unknown Child
  - b. Notification Closed Child
  - c. Notification Level I Child
  - d. Notification Level II/III Child
- 20) The Notification communication will also documents the referral from the source to HCP. Viewing the referrals will show the notification referrals from outside program sources.



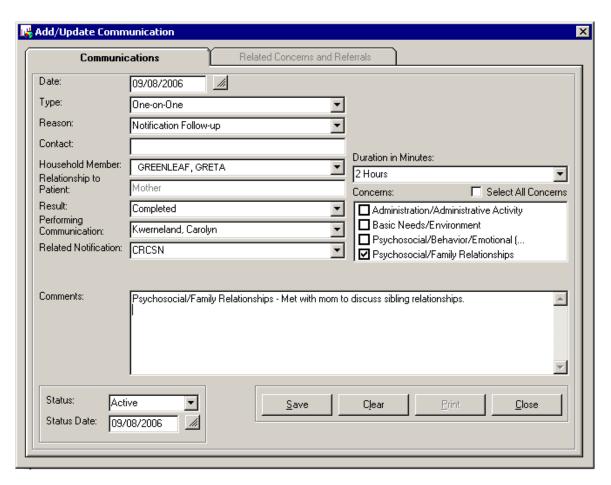
- 21) CRCSN Data contains and will Add or Update the child's record in HCP/CHIRP in the following way:
  - The name of the child and birth date in the Patient node.
  - The name of the guardian listed under the Family node.
  - The address and phone under the Household node. It will be an additional address for the household if there was already an address entered previously.
  - If the child is identified from birth certificate data rather than from hospital discharge data, the first line in the comment field will read "Source is Birth Certificate".
  - CRCSN has the option to transmit up to two special messages that appear in comment field. These are available to assist with follow-up.
  - The date of the diagnosis, length of stay and the site along with the ICD9-CM code and a literal description of the code appear in the Comments field on the Notification Communication. This gives the RO Staff the option of entering one or more of the diagnoses for the child in the diagnosis screen.

NOTE: If the child transferred to or is located in another HCP site, the HCP staff should transfer the case to the appropriate HCP site. The site where the child is currently living is the HCP site that should perform the REPLY.

The Process of HCP replying to the NOTIFICATION from CRCSN.

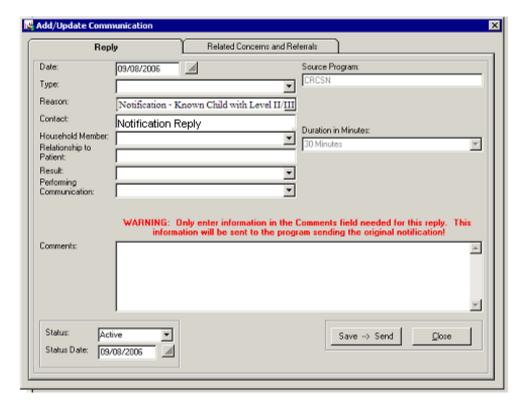
HCP staff completes the triage process to determine the type of follow-up needed or to decide if no attempt will be made. Each contact or attempted contact with the family is documented in a Communication in the child's record. Replying to the notification needs to wait to see if the family responds to correspondence and/or previous attempts. The care

coordinator makes a decision on when enough information is known to complete the Reply to CRCSN.



1. To relate a communication with the appropriate communication, select 'Notification Follow-up' for the reason and an additional dropdown will appear giving the user the capability to select which notification this communication is for.

2. When ready to reply to the CRCSN notification, the user clicks on the Reply button and the Reply communication screen will appear.



- 3. The system will
- 4. Populate the Reason with the same value as on the Notification communication
- 5. Total all the time spent on the Notification Follow-up communications associated with this Notification and put that amount in the duration.
- 6. Respond by filling out the Reply screen in this manner:
  - Type in today's Date (by clicking the box after the date field) to document the date of the reply to CRCSN. This is the date when the care coordinator knows the result of the notification follow-up or knows that no further efforts are going to be made.
  - Select the TYPE of communication that is the highest level of contact made with the family (types are numbered with #1 being the highest level and #5 the lowest level of communication):
    - 1-One-on-One
    - 2-Phone Call
    - 3-Correspondence
    - 4-Consultation
    - 5-No Communication
  - The Reason will be populated by the system to reflect the status of the child with respect to HCP when the Notification was received.
  - Select a CONTACT (you must enter either a family member or enter something in the contact field to save and send the reply):

- o If a family member was contacted, you can select that person from the drop down of Household Members.
- o If no family member was contacted, or if no one was contacted, just enter a description in the Contact field, like:
  - None
  - Neighbor
- Select a RESULT (on Reply Screen):

Reply Results	Description
HCP Level 1	Provided Level 1 to an any child (know or unknown)
HCP Level 2/3	Currently receiving or starting HCP Level 2/3 Care Coordination
Already in Non-HCP Services	Family indicates they are receiving services from other source.  Does not want or need HCP services
Family has No Concerns	Family not concerned about child's health and development. Diagnosis is not known or appropriate according to the family.
Child out of Home	Child adopted or in foster care. Unable to contact foster family
Terminally	Family shares the child is terminally ill or deceased
III/Deceased	Does not want or need HCP services
Moved out of state	Family is known to have left the state.
Lost to F/U	Phone disconnected, insufficient address and mail returned by USPS
No capacity	HCP office unable to provide follow-up due to capacity issues such as vacancies or other public health issues (e.g. H1N1)
Diagnosis Low Priority	Diagnosis is determined to be lower priority for follow-up due to staff priorities/capacity. <b>Use only if diagnosis is low priority</b>
No Response from Family	Left phone message or sent letter that wasn't returned undeliverable plus a 2 <sup>nd</sup> attempt that did not result in family response.

• Fill in the Performing Communication field:

The default is the User ID of the person signed on (usually the care coordinator). You may enter another persons name if you need to.

- The System will populate the Duration In Minutes by totaling time for all communication done as part of the Notification Follow-up (Consultation with others, Correspondence, Phone Calls, and/or One-on One). This time will include the 15 minutes for the original Notification Communication and the default of 15 minutes documents for the effort of completing the electronic Reply.
- Comments Enter appropriate comments to be directed back to CRCSN.

WARNING: Only enter information in the Comments field needed for this reply. This information is sent to the program sending the original notification!

- Clink on the SAVE → Send button.
  - 7. The HCP Reply data is processed through the NEST and the data is routed to CRCSN. This replaces the hard copy Notification Form previously sent to CRCSN.
  - 8. A Communication is generated by the System and shows in the child's record with the Reason "CRCSN Notification Reply". This documents that the Reply was completed. It can be opened and viewed but not modified.

HCP CHIRP REPORTS – these reports assist care coordinators with Notification Follow-up and the HCP Regional Office with oversight for Regional Notifications.

- 1) CRCSN Notifications Current Lists all the current notifications received during the month entered in the Report Request Screen. Example: 8/1/06 shows all the notifications received during August.
  - 2) CRCSN Notifications Outstanding Lists all the notifications that have not been addressed with a REPLY. Example: 8/1/06 shows notifications received before August that have not been addressed with a REPLY.

## **Key Contacts**

If you encounter a family with questions or concerns related to confidentiality, consents or HIPAA, we encourage you to ask if they would like to be contacted by either Margaret Ruttenberg or Carol Stanton from the CRCSN program for additional clarification and information. They can be reached at:

Margaret Ruttenberg, Director CRCSN Program Manager, Environmental Health Studies and Colorado Responds to Children with Special Needs (CRCSN)

Phone: 303-692-2636

E-mail: margaret.schonbeck@state.co.us

Carol Stanton, Medical Information Manager, CRCSN 303-692-2621 carol.stanton@state.co.us

For questions about information you receive in the CRCSN Notification in the CHIRP database, contact:

Charla Low 303-692-2423 charla.low@state.co.us

For questions and support regarding available community services and resources, please contact either your assigned HCP regional office team leader or Jane Gerberding at the state office.

Jane Gerberding 303-692-2024 jane.gerberding@state.co.us

